



State of Louisiana

Louisiana Department of Health
Office of Public Health
Louisiana Sickle Cell Commission Meeting
July 29, 2020
10:00 a.m.-12:00 p.m.
<https://ldhophbfhgenetics.zoom.us/j/92751837270>
Conference Call info: (602) 333-0032
Access Code: 532143#

Roll Call taken; members present at the meeting were as follows:

- Renee Gardner, MD, Children's Hospital, New Orleans
- Amino Rafique, MD, Sickle Cell Center-Tulane University
- Pamela Saulsberry, Ph.D., LCSW, Northeast Sickle Cell Anemia Foundation
- Shannon Robertson, RN, BSN, Louisiana Primary Care Association
- Chauncey Hardy, Sickle Cell Anemia Research Foundation, Alexandria
- Erin Fulbright, Sickle Cell Association of South Louisiana
- Cheryl Harris, MPH, OPH Genetic Diseases Program (LDH Designee)

Additional meeting attendees:

- Melody Benton, Sickle Cell Center-Tulane University
- LaTarsha Carter, Healthy Blue
- Kathy Williams, Sickle Cell Association of South Louisiana
- Torris Johnson, Sickle Cell Association of South Louisiana
- Rajasekharan Warriar, MD., Ochsner Health Center for Children
- Alishia Vallien, Southwest Louisiana Sickle Cell Anemia, Inc.
- Jasmine Mosley, Southwest Louisiana Sickle Cell Anemia, Inc.
- Marquita Brown, Southwest Louisiana Sickle Cell Anemia, Inc.
- Courtney Sanford, Louisiana Primary Care Association
- Erica Rose-Crawford, Louisiana Primary Care Association
- Kelly Hess, Global Blood Therapeutics, Inc.
- Horatio Handy, Global Blood Therapeutics, Inc.
- Shawn Henderson, Global Blood Therapeutics, Inc.
- Brent Young, Global Blood Therapeutics, Inc.
- Patti Barovechio, DNP, MN, OPH Bureau of Family Health
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
- Sharonda Smith, OPH Bureau of Family Health
- Rachelle Boudreaux, MA, OPH Bureau of Family Health
- Michelle Duplantier, LCSW-BACS, OPH Bureau of Family Health
- Kera Simmons, MPH, OPH Genetic Diseases Program

- Chelsea Carter, MPH, OPH Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program
- Albaney Gray, OPH Genetic Diseases Program MCH Scholar
- Caroline Werenskjold, OPH Genetic Diseases Program MCH Scholar
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Jantz Malbrue called the meeting to order at 10:05 a.m.

Welcome

Approval of meeting minutes – March 25, 2020

1. Data and Surveillance- Jantz Malbrue
 - a. Surveillance System/Registry Model

SECURE-SCD Registry

The Medical College of Wisconsin created a registry to track all cases of COVID-19 for sickle cell disease patients. Clinicians are encouraged to report ALL cases of COVID-19 in their sickle cell diseases (SCD) patients, regardless of severity (including asymptomatic patients detected through public health screening), to the Surveillance Epidemiology of Coronavirus) Under Research Exclusion (SECURE)-SCD registry. The project website, <https://covidsicklecell.org/>, provides regularly updated summary information about reported cases, including numbers of cases by country, number of cases by treatment, etc. so the entire SCD community has access to these data. To report a case of coronavirus, please visit <https://covidsicklecell.org/>. If you have any questions, please reach out to Covid.sicklecell@mcw.edu.

COVID-19 Among SCD Population in Louisiana

Totally 111,038 cases in Louisiana (COVID-19 Impact). Leading per capita so far 269 cases reported and nine from Louisiana. No breakdown for our specific state due to patient information and confidentiality. Large majority experiencing pain and pneumonia, 12% experiencing renal failure.

- Effective treatment – medication and interventions helpful to recover. Website has other great aspects; tracking gender, sex, medical history and other treatment/intervention options.
- Providing data weekly on website “covidsicklecell.org”.

2. Medical Service/Delivery

Project ECHO

Innovative telementoring program designed for virtual communities. Geared towards case based learning. Improve patient care outcome, tool used. Multidisciplinary partnership: using technology similar to Zoom (videoconferencing)/face to face

mentorship. System that allows for experts to educate and provide larger network of individuals providing care. Discussion with Dr. Warriar, who is working through Ochsner, is willing to allow us to join to create a statewide program through Sickle Cell Anemia about twice a month one hour session – 1-2 a month; Social Worker, Hematology, Psychologist, etc. Dr. Rafique from Tulane agrees with Dr. Warriar and states that she attends Virginia University for Echo. Presentation is great idea. Question: Will it be for pediatric and adult patients? Statewide program would be for everyone working in New Orleans area. Dr. Rafique is happy to help in any way and Dr. Warriar is ready to get started. They are interested in strengthening and developing more pain management protocols.

SAFER Steps (NIH)

Six-page pain management tool adopted from AHRQ & NIH. Pain algorithm for patients to follow. Idea: creating small pain management tool; maybe one-pager, next steps for treatment/medication options, which would be more helpful for individuals. Per Mr. Malbrue, he just wanted to get group thoughts and ideas on creating a tool, editing/reformat to fit the needs of individuals here in the state. On reason for having this would be to make available for providers in emergency rooms, those who come across individuals, lack of education and also other providers that care for Sickle Cell individuals. Move more towards accurate steps to take rather than spending unnecessary time in emergency room. Chauncey Hardy, Dr. Warriar and Dr. Rafique believe this is a very nice tool.

- Could be something more specific for patient possibly on pop up screen in electronic record. Epic has ability to do this. Done for each patient. Can easily be done in hospital ER. Great idea!
- Development of pop up screen to work with hospital administrator; add to Epic. Comprehensive care for Sickle Care patients from previous meeting with Epic. Sonar can do this too. Questions: Is this something primary provider can do for pediatric patients? Could he enter info to show up at hospital or something he would give to patients to take with them to the emergency room? How would this part work? Response: Many programs can do this.
- Pain management: LaTarsha Carter discussed pain management tool delivered correctly, but education providers to receive for tools available to them. Education piece given to them. Educating someone to use correctly is the key, so that care can be delivered to ensure no gaps in care. Education is definitely key and adding types of tools of epic to make sure providers and others are utilizing tools and understanding how to use another component about resources for patients, doctors, etc.
- Dr. Gardner – Attempting to put together similar type of algorithm for pediatric patients coming into emergency room. Would like to coordinate/share ideas with Ms. Carter.
- Kathy. Williams – recently clients getting different problems with pain. Client dissatisfied with treatment. Good for patients to call and get more guidance which we should prevail on actual treatment of client? Who should take precedence? Patient feels they were not communicating with each patient preferred full dosage at the same time. Dr. Gardner responds to question. Don't

- want patients to develop dependency on just medications. Not overwhelming need for pain medicine, all the time. Example given concerning patients and parents not wanting pain medication only. There has to be coming together of minds of care givers and patients for overall goal. She wants patients to get off of medication, so that they are not controlled or obsessed with pain meds. She has patients who have been on five different pain medications at one time.
- Goal – What are you trying to achieve with this? Per Dr. Warriar, chronic pain is a little different (very difficult to handle). Acute pain totally different. Want to have patient develop well without developing dependency for medicine. Dr. Gardner states care givers should be talking with other care givers and patients. This is where self-advocacy comes into play. Actively in their care or children's care. It's their right! Health care is a right and not optional. Advice: If you don't have a physician that won't listen to you, you should find another physician. Per Dr. Warriar, education and support is very important. Education and advocacy are great points.

3. Report: Education and Advocacy

Example ID Cards

Emergency ID Cards to present and for individuals to have on themselves and share. Two examples of emergency cards – small double sided card. One is split fold pocket card with little more detail.

- Dr. Gardner uses something similar to second example. She will send to Jantz Malbrue. Includes basic information on card. Will show everyone what it would look like in the next meeting. Kathy Williams states this is something that could be put in school file for kids upon returning patients could give to nurse at school for their file. Dr. Gardner states that they send a letter to parents to give to the principal/teacher at school for their files to outline their needs. Chauncey Hardy believes both ideas would be great. He also states that if a child has ability hold on to the card this would be great. Dr. Warriar states letter to school, plastic to hold card are all great for patient. Mr. Malbrue gave example of card with chip on end used to pass more information. Kathy Williams mentioned medical bracelets for small children, but were not very popular in the past. LaTarsha Carter reports child with some type of illness required to do treatment plan. Patient has a sit down with staff and nurse to discuss. Treatment plan that is required and everyone is aware. There is also something at school level that has to be done to ensure things are taken care of before students actually sit in a desk. Also happens at some of Head Start programs. Mr. Jantz will follow-up with our SBHC person to find out information. Per Dr. Rafique, due to COVID-19 are you all sending out letters to the schools or sending out letters to patients? Dr. Gardner states some parents felling uncomfortable if the child has any deficiency/incompetence probably should think about sending the kids back in. With Sickel Cell, don't know about sending our kids back. She has been telling people if you are having concerns about class size or concerns about sending your child to class, it may be a good idea to keep them at home if you have the ability to do so. Nothing official at this time.

- Cheryl Harris informs everyone that they are having an axillary meeting to make recommended guidelines for patients in Louisiana perhaps to funnel up to LDH for approval or formal recommendation. She states her need to have a meeting of the minds from the data we have to talk about what we should be telling people. LaTarsha Carter gives example on personal note concerning registering for school, giving choices. Cheryl Harris to set-up meeting and send an invite.

Awareness Month Activities

Mr. Malbrue reminds us that September is Sickle Cell awareness month. He states the probability of doing something virtually if others are open to statewide conference or smaller with experts, patients, and families to share stories. And possibly early 2021 an in-person statewide conference. Gail Gibson encourages going virtual whenever possible. Don't want to wait until next year to do something in-person. Dr. Warrier offered to work with speaker in different fields for September or October. Jantz Malbrue will coordinate with everyone else. Come up with virtual schedule, set-up a time for more cohesive statewide event. He will work on this and send out plans to everyone soon.

4. Legislative Report

House Bill 591- Louisiana Sickle Cell Commission Changes

Expands number of appointed members to commission and location to meet. Allow to meet outside of Baton Rouge. Expand and add as many members as necessary/ wanted. Extended to five Government appointed new members to include: a) one person living with Sickle Cell. b) One Parent living with person with Sickle Cell. c) Two medical professional and d) one representative from Louisiana Medicaid Program (someone to give more insight and help us move forward). It has been approved and signed by the Governor.

House Bill 819- Medical Marijuana Treatment Expansion

The bill was passed and sickle cell disease was now included as a chronic pain condition approved for medical marijuana. This is another avenue for patients. Question: Does this mean we can now write for larger quantity of Opioid medications? Jantz Malbrue will follow-up to see if there are any answers for prescription medication. He will be updating commission guidelines and bylaws to share with the group. He will also work with Governor's office to make sure he receives updated information.

5. Genetic Diseases Program Update

Cheryl Harris to give updates regarding Department of Health and Genetic Diseases Program. She states that we are continuing to support Sickle Cell activities. This year was General session and next year will be a Fiscal Session. If this commission would like to propose to LDH for consideration, now is the time to start thinking

about the next fiscal year. Looking at clinical improvements due to COVID-19. Sped up efforts to conduct Telehealth to regional clinics. In April, initiated Telehealth. Those visits seem to be going well. Also looking at patients in Regions with LCSW doing behavioral health assessments. Lastly, still trying to work on funding for patient navigator program for Fiscal 21 budget; waiting to see if budget approved by LDH. Questions: Chauncey Hardy states he has \$35,000 budget and other CBO's budget is similar. Concerned that \$35,000 is short for running community based organization. Looking at each contract and doing an analysis of the cost benefit and service delivery of each contract. Per Ms. Gibson, we are going through all contracts to see how they are aligned with deliverables, and best way to meet those needs. State struggling now due to COVID-19 expenses and significant juggling trying to balance budget, address critical concerns, etc. Trying to maintain all funding for current contracts. She understands how valuable everyone is, but still only so much money to divvy up. Gail Gibson states the following: There is no plan for change or move in different direction right now. Current contracts were extended and continue with current providers until further notice. Question: Is Medical Marijuana covered with Medicaid? This is fairly new and don't know as of yet. Just approved most recent session.

6. Other Business

Announcements

- Kathy Williams asked that you keep family in prayer because two leaders lost in 2020 Sickle Cell community. She mentions that September 26th is virtual run/blood drive in memory of Ms. Burgess.
- Dr. Saulsberry shares information about campaign entitled "Exercise your Faith". Similar to "Use Your Head to Stop the Spread." Initiative to help get better healthcare education to individuals in the communities. The campaign targets African American community/work through Faith-based organizations, Barber & Beauty Salons, Medical professionals, etc. providing information needed to help individuals with mind, body and pain issues. Dr. Saulsberry will provide information for health fairs, nutrition, healthy living styles, etc. People in New Orleans, Baton Rouge Central and North/West Regions. Can send to individuals on commission (Sickle Cell foundations). Jantz Malbrue happy to help!
- Parent information packet that is shared to school would like to see some of the letter that others spoke about. Help parents to be better advocates. Mr. Malbrue will see if he can get copies of the letters for resource.
- Kathy Williams discussed survey on Medical Marijuana and gave examples. She states parents are willing to tell their stories.

Adjournment 11:50 AM